

January 19, 2006

State of Connecticut General Assembly  
Committee on Public Health  
Legislative Office Building  
300 Capitol Avenue  
Hartford, CT 06106

To the Members of the Committee on Public Health:

My name is Patricia Lang. I have been the Director of the Rhode Island Blood Center Marrow Donor Program since 1991. We are a donor center in the National Marrow Donor Program whose mission it is to facilitate the donation of marrow/stem cells from unrelated donors to patients suffering with various diseases. The federal government contracts solely with the National Marrow Donor Program to carry out this mission according to the requirements of federal law.

In 1998, the Rhode Island State Legislature passed a law mandating that health insurance plans written in that state be required to pay the cost of Human Leukocyte Antigen (HLA)-A,B, and DR typing for volunteers willing to join the National Marrow Donor Program. This test needs to be done just once in a person's lifetime as this type never changes. By the end of 1998, the Rhode Island Blood Center was taking donor insurance information and invoicing the insurance companies. There was a learning curve but the process is very manageable and straightforward.

On December 28, 2000 the Governor of Massachusetts signed into law a similar bill. And on May 26, 2006 the Governor of NH signed a bill put forth in that state. In RI we find that health insurance will pay for about 80% of all volunteer donors. That leaves us with a small number of donors for whom we need to find funds to cover the cost of HLA typing. We have shifted our focus from raising funds for donor testing to the all important emphasis on donor education.

There are several reasons why I continue to support legislation of this type.

First, it serves such an important need. Bone marrow transplantation is increasing as an effective treatment for many patients with more than 60 cancers who fail to be cured with chemotherapy alone. We can expect a further increase in its use over the next few years.

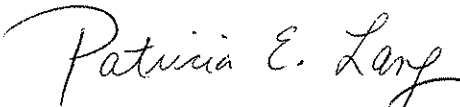
Second, patients needing a transplant will find a matched donor within their family just 30% of the time. Most need to search the National Marrow Donor Program for a volunteer unrelated donor. Even after searching the National Registry, many patients, especially minority patients, do not find a match and may search for months or years before a suitable donor is found. During this time, a family often holds marrow donor recruitment drives in an attempt to find a donor for their loved one or to help any one of the thousands of patients who are continually searching. In every state but Rhode Island, Massachusetts, and New Hampshire the family must raise the funds to pay the cost of HLA typing. This is a terrible burden at a time of stress.

My third reason to ask health insurers to pay the cost of HLA testing is that I believe that they will save money in the long run. With a larger number of registered, HLA typed donors, patients will find a match quickly. This translates into reduced donor search costs (usually paid by the insurer) and a transplant that can be done while the patient is in remission. A patient who is healthier at the time of transplant has had less time in treatment (reduced costs) and experiences fewer side effects during the transplant (reduced costs). This patient returns to a healthy state more quickly and becomes a working, tax paying citizen once again.

And finally, we should support this action out of a sense of community, people should and do care about each other. Our country would be well served if we could facilitate voluntary entry into the National Marrow Donor Program at no cost. After all, we don't ask blood donors to pay for the opportunity to give blood.

I encourage swift passage of this important legislation and will answer any questions you might have. Thank you.

Sincerely,

A handwritten signature in cursive script that reads "Patricia E. Lang".

Patricia E. Lang, MS, MT(ASCP)  
Director of Rhode Island Marrow Donor Program  
401-453-8566